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THE PATIENTS VOICE AT THE MILLENNIUM

God said, 'Let there be light', and there was light

Murray Munro Tyrrell

Epilepsy sufferers are always told that each person's epilepsy is a personal story and that each form of epilepsy and its manifestations are in some ways different from others. I much prefer it this way. It is just such a pity that on approaching the third millennium, the general public still do not view it this way. By this latter term, I intend people from all nationalities, from different social backgrounds, of both sexes and from academics to people with learning difficulties. I could go on.

It is a sad defect of human nature to overgeneralize. As a Saudi diplomat once said to me. 'The world could be a happier place if people could stop creating stereotypes of people: not all Italians are lazy, not all Scots are mean, not all Arabs are terrorists etc.' He could well have added that not all people with epilepsy are of low intelligence, erratic, aggressive, pious as Bertrand Russell once wrote and so on.

I have perhaps surprised the reader by mentioning academics. By and large their comprehension of illness can be more comprehensive but certainly not always. My first attempt at university was a failure. I almost did enough to pass on to second year but not quite. Settling into and adapting to new environments has always been a problem for me, perhaps less so now than before. A medical physician appealed to the university senate to consider my case with understanding and humanity. The university refused to be moved and I had to depart. To this day, I have always said that I would have passed had I been given a second chance. Only very recently that same university was in the media after a number of students maintained that their welfare interests had not been and were not being taken seriously enough by the university. A public statement from the university said that it dealt with and had always dealt with students' problems with the greatest of understanding. Academia, therefore, can also show at times its cold and unsympathetic face.

Returning for a minute to overgeneralizing and stereotyping people, a further point should be added. I was recently talking to a senior member of the British Government and he told me that a recent survey or questionnaire amongst would-be employers showed that they were often more ready to employ somebody with a criminal background than somebody with a disability. I reflected on this. Certainly a man or woman who has paid the penalty for having committed some crime should be given every fair chance to be readmitted into society but why this strange attitude towards people with disabilities? They often totally fail to see that such a person's work output along with his or her loyalty to the employer could far outweigh any inconvenience caused by employing that person. Sadly, too few people have that patience, understanding and insight which is needed to enter into the world of that disabled person and make him or her feel at home in every possible way.

Another recent survey showed that a substantial number of people believe that wheelchair-bound people are of inferior intelligence. How much worse it probably is with attitudes towards sufferers of epilepsy, autism and other 'hidden disabilities'!

What do these examples show and why do I mention them? For me it sadly demonstrates the reality of much of the so-called advanced Western Society which reputedly has left behind the age of religious myths, stories of epileptics possessed by demons, through the age of enlightenment and passed into a period of post-enlightenment but in reality is still suffering from a high degree of unenlightenment, lack of understanding and lack of vision both in depth as well as in breadth.

Where, therefore, can we find that real light of understanding and vision? Not necessarily in the church or in religious groups, not necessarily in the schools or in the universities, not necessarily in the middle classes but simply amongst people, not necessarily of high intelligence, who merely go through life with that often rare possession of warmth and human understanding. They are sadly in the minority and here, I believe, I am not being unduly pessimistic.

This little story is by way of a personal confession. Quite recently I was waiting in a queue of people in a

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shop and a black person pushed his way to the front. I muttered the most terrible expletives under my breath about a worthless black person and so on. I was immediately filled with remorse. I had always prided myself on being open to all groups of people, irrespective of race, disability, religion, sex, sexual orientation, etc. I suddenly realized that lurking deep inside me was a little black spot, a spot which I had not purged or come to terms with. I could also discriminate and yet I was crying out to people not to discriminate against people who suffer from epilepsy. That little black spot lies to a greater or lesser extent in most of us. Perhaps we should try to tackle the whole area of discrimination with its causes and effects without looking at it in one single field such as epilepsy.

On-going medical research in the treatment of epilepsy is of huge importance but the greater task that lies before us is that of enlightening people's minds. Knowing the facts of epilepsy or any other area of discrimination through education is only one part of the story. The other is seeing it brought into practice. That solution is an ethical one perhaps even a religious ethical one whereby all our 'I–Thou' relationships with people, as Martin Buber defined them, should be the object of our love and our compassion which show that we share their suffering because we know about them as people. These relationships will very often be with people different from ourselves whether it be on the grounds of physical and mental abilities, sex, religion, general socio-political beliefs, race, sexual orientation, etc. Only then, and ultimately not through legislation, can we really live in a healthy society free of discrimination. I am trying on a daily basis to develop that inner life. Hopefully I will never utter such things again against a person who happens to be different!

I have recently read Dostoeysky's 'The Idiot' for a second time. It is a wonderful story. One could easily point the finger accusingly at the author because he perhaps thought of himself as morally superior to all the others in his society. This attitude could also be said to be found as the legacy of the reformed Christian tradition so wonderfully portrayed by the Scottish poet Burns in his 'Holy Willie's Prayer'. There is both a little of Prince Myshkin and Holy Willie in me, I suspect because of my medical condition and because of the fact that I have grown up in a Scottish reformed culture. One of my struggles has been to find a place for myself not on the twilight peripheral zones of society, not in the centre of society itself, but merely, warts and all, with and alongside all other people.

Any classic in the Arts is such because it endures time and space and can transcend all national boundaries and mean something to many people in many different countries of the earth. A work like 'The Idiot' does not merely belong to that great library of Russian writers but is equally a part of that corpus of world literature. Why is 'The Idiot', therefore, a classic? The way Prince Myshkin was treated in nineteenth century Russia can be equally the case today. People with epilepsy can still be regarded as idiots or at least semi-idiots more than a century after Dostoyesky was speaking to us. That light of the Enlightenment of which I spoke earlier can take a long time before it really illuminates peoples' minds.

People were either very slow or incapable of realizing Prince Myshkin's considerable intelligence and how much he had to offer his society despite his disability. Some gradually learnt it towards the end.

What meaning does that have for us today? A considerable meaning, I should say. Perhaps all people in society, including would-be employers, should buy a copy and read this work carefully. They should perhaps ask themselves honestly whether they can identify themselves with any of the characters surrounding Prince Myshkin and whether they treat the disabled, the infirm and in this specific case, the epilepsy sufferer in the same way.

At this point I might sound somewhat arrogant. It is not my intention. I have been unemployed for some time. One or two perceptive people have asked me why I think this to be so. 'Is it because of my years (I have passed the age of 50) or is it because of my history of epilepsy?' This is a very difficult question to answer honestly. Ageism is a real problem in today's job market. That is undeniable. After long thought and consideration, however, I replied that my position would be different today had some enlightened employer been able to see beyond 'my warts' and had been able to see what I could offer. I have no doubt that I am and have been a victim (perhaps an emotionally overloaded term) of man's narrowness of vision and of how, as that Saudi diplomat said, man can overgeneralize about groups of people. Ignorance can be man's worst enemy. Prince Myshkin lives on in Western society. I am not a social anthropologist and have little or no idea how epilepsy is regarded in less developed societies, by that I mean economically not necessarily humanly.

At the beginning, I spoke about how every history of every epilepsy sufferer was different. This is so, I am sure, but human beings do share things in common. The essence of democracy is freedom. Freedom of speech, of thought, of movement, etc. should be the basis of any healthy and well-developed society. That is why communism showed that it was constructed on a far from sound foundation. The political system toppled so dramatically and easily. What is the relevance of freedom here? It is in my opinion very relevant. We in our democratic societies are faced with all sorts of frightening legal-moral choices, none more so that in the field of genetic engineering and embryology. Another is when a young woman with perhaps

severe learning difficulties wishes to follow her natural instincts and have a child. Should our society legislate against that young woman's freedom of choice? I should say quite firmly that we shouldn't. An adult and morally mature society should be able to offer all support necessary.

When I was young and collapsed for the first time, my parents like any other good parents in a similar position had to face the question as to how much freedom I should be allowed to enjoy and how much freedom I was capable of coping with. The medical profession was divided. Some said that I should more or less be collected after school lessons and brought home where a constant eye would be kept on me. Considering how important childhood development is; running around, bonding with friends, playing different sports, sitting in cafes, listening to music and discussing etc., it might have created a rather bleak future for myself, turning me into some socially unintegrated outsider, friendless and with his books or some other interest as his sole companion. I did in fact once know an epilepsy sufferer who lived in just such a way.

I was much better than the average at sport. The other half of the medical profession whose advice was also sought said that I should be given as much freedom as any other child, even if it meant having a seizure on the rugby pitch. In retrospect, this was absolutely the right decision to make. I lived my life to the full on the rugby pitch, on the squash and tennis courts and in the mountains. I can look back with deep gratitude to those enlightened doctors and to my brave parents, dead now, who gave me that chance. In many ways this short tract is a dedication to them. When I occasionally meet old school friends years later, they still remember me as 'that flying wing' or 'top-level squash player' and not as some mysterious bookworm who had always been ferried backwards and forwards to school. Every epilepsy sufferer should be given every possible opportunity to develop his or her God-given skills.

My parents obviously took that decision to give me that freedom with considerable difficulty and I am sure agony, not easy for any loving parent towards a loved child. How difficult these choices are when parents are asking themselves whether their son or daughter should be allowed to do certain things. I do believe that parents should often be more ready to take these risks, within reason of course, rather than erring on the side of over-caution. They should look very closely at themselves as to why they are making certain decisions. Is it for the real good of their child or simply for their own peace of mind? These are difficult questions to answer honestly. Being an overprotective parent can leave permanent wounds in any child no less so in any child with epilepsy who is trying to develop into a responsible, mature and well-developed human being.

Apart from my by now well-controlled epilepsy, I also suffer from severe arthritis of the hip, probably as a result of many years of sporting activity. What has always surprised me is that most of my friends, many of whom can be counted as people of high intelligence, have never over a period of many years asked me any intelligent questions about my epilepsy. They do about my arthritic hip and seem interested in possible difficulties I might encounter and what aids there might be available. I wonder why this should be so. It is because epilepsy is in most if not all levels of society a taboo subject, one to talk sparingly about if not to be avoided completely. Some people seem to find it difficult to articulate the word and prefer using such alternative expressions like 'You know what I mean' or they simply look embarrassed.

I was recently arguing with a close member of my family about discussing personal health problems directly with people. I was accused of seeking too explicit information regarding medication, long-term prognosis, pain etc. I am fully aware that such attitudes will vary from one culture to another (the Northern hemisphere can differ from the Southern one) and that there are proud souls who just do not want to admit that they might have any physical, mental or emotional problem but I am ever more convinced that most people do want to talk about their difficulties as long as they feel comfortable and not threatened or pushed. Almost nobody has ever asked or asks me about my epilepsy, the frequency of attacks, whether I have any warning, what my mental and physical suffering has been, what medication I take, what social problems I encounter, including employment etc. I could go on and on. I would love to tell people were I asked, in the same way that other people want others to understand their problems with sympathy and understanding.

It would however appear, at least in part, obvious to me why so many in today's world are unenlightened and live in semi-darkness. It is because they do not ask, are afraid to ask or perhaps are merely uninterested. This information must be communicated, after all we live in a world of ever-expanding communication systems. It is there that we can often find the roots of prejudice, discrimination and bigotry. How often do we find this in today's world in questions of religion and other conflicts? In a sense an epilepsy sufferer's position vis-à-vis society is also a conflict one and is based on ignorance.

We love to have heroes and icons in our lives but sometimes it is not always helpful. As one broadcaster said, 'A mature society should do without them.' I must admit that I feel strengthened when I read about world class sportspeople who have and still suffer from epilepsy. A close friend of mine who admitted her ignorance of epilepsy but who loved cricket, suddenly understood that people with epilepsy could

emerge in all areas of life, including top-level sport.

I was once at a national meeting of The Epilepsy Society and a senior company manager appeared on the stage. He proudly spoke about reaching his position despite his epilepsy. How many people with epilepsy let alone without can become top company directors, sportspeople, writers, musicians, artists, scientists, not to mention Caesars, Napoleons, Alexanders and so on? Not many. Maybe these people should not be our heroes or icons but those people with epilepsy who are succeeding in the everyday struggle of life, to work and to play a useful part in society.

One of the difficulties which epilepsy sufferers can face and which could appear as bizarre to the outside world is that, because it is a hidden illness, they can seem to be perfectly normal but in their hidden lives might be struggling to overcome some very real difficulty which he or she is never given the opportunity to explain to the world. To the outside world and here I would include the medical profession, I was living a perfectly healthy, balanced and indeed normal life. (I should use the word normal with a certain care but I have no intention here of debating what is normal or abnormal.) Nobody ever realized that frequent seizures had made me very forgetful and lacking in any proper sense of order and responsibility to face everyday demands. Managing and organizing paperwork had become a nightmare for me. I fell years behind in my tax returns. Most people looked on me as an intelligent person who could cope and I was perhaps too proud to tell somebody that I couldn't. I do often wonder on looking back how sympathetically I would have been treated by the Inland Revenue if I had approached them and said that, despite my intelligence, I had little real control over my everyday affairs and that frequent epileptic seizures had created in me a sense of forgetfulness and lack of responsibility towards everyday matters. This could have created an interesting dialogue between the tax officers and people working in the caring professions.

We, the public, and the medical profession can all too often judge an epileptic's well-being from the seizure frequency. Much work should be done to look at that inner life of the sufferer. I was admitted to hospital on many occasions after an epileptic seizure. The doctors would automatically ask whether I had taken my medication. I invariably had. No more interest was taken. I would be discharged and that was that. If they had asked me about alcohol, they might well have received a different reply. I had probably drunk too much alcohol the night before. Why? Perhaps it was a comfort to me with all my inner problems, my lack of good employment and a general lack of self-esteem and confidence. This area was rarely if ever explored. Medicine with its ever-increasing specialization can often forget to look at the patient in a holistic way. In the long run this might improve the chance of cure. Pharmacology for all its worth is only a part of the story.

A human being is by and large a conformist, probably because he or she can feel more secure when conforming to the patterns and conventions dictated by that society in which that person lives. Conforming varies by degree. We can be brought into line by our school, our church, our party chief whip, our employers and we should accept these rules if we want to be accepted. Dostoyesky was an outsider just as many people with epilepsy before and after him will be. We, and I include myself, create our own worlds. I try to look at myself and society truthfully and in good faith. It is little wonder that the honest thinker or creator can often be the Aussenseiter or the outsider. Truth searching and constant thinking can appear as a disease to some people. Many simply get on with their lives, have families and friends, play a useful part in life and ask themselves at times what life is all about. Even if they obtain no immediate answer, they can simply carry on. That is what society generally expects from its members and that psychologically has often been my problem.

Epileptic seizures can mean terrible disruption of thought processes and the person with epilepsy often has to construct his or her Weltanschauung or view of the world. Prince Myshkin tells us how a doctor in Switzerland had tried to help him for 4 years. His epilepsy might not have been cured but he did perhaps come back to mother Russia with a clearer understanding of life. Freedom, as I mentioned earlier, has been the basis of my development. Sometimes in my darkest moments I wished that I had been educated at the feet of some Jesuit priest as the young Plato had been educated at the feet of his master Socrates. I was not and in retrospect I am glad that I was not.

The intellectual education of somebody with epilepsy can be a considerable problem. The freedom of normal schooling is always recommended but perhaps extra classes should be given in psychology, philosophy and religious thought, disciplines which are sadly lacking in our school curriculum.

The person with epilepsy, that individualist, that creator, that independent thinker can often find it very difficult to be accepted into a society whose values that person seems to be rejecting if not positively scorning. He or she has become like that because society has often turned its back and failed to recognize that person's attributes.

Politicians, statisticians and others wave their arms with glee when unemployment figures fall not only in this country but also in the countries of the European Union or in the industrialized world as a whole. We are obviously affected at a global level. These same people fail to look more closely at jobs in general. For

a start anybody who knows the Mediterranean world knows how difficult it is to know the level of employment with any accuracy as there is such a strong black market. We can often become obsessed with getting people into work irrespective of how suitable it might be. The government in the UK is trying to get the disabled back into the job market. This is laudable and I would fully support it. One thing, however, which is not considered is that people with epilepsy or any other disability can cover an extremely broad spectrum of intelligence and abilities. Too often these job providers can see disability as being synonymous with low-level intelligence and work can be found accordingly. Governments and people who are seriously engaged in helping the disabled to find work should take serious note of this. In our everyday lives, I have sadly noticed that we can often make poor value judgements about others, very often based on prejudice and a certain narrow-mindedness. These pages should be seen as an appeal to people the world over to see that in some if not in many people with epilepsy they can choose people who can make a considerable contribution to their society.

Feminists can seem to support blindly all others of their sex. Naturally people will support others in their particular group which might well be a minority one. That is not my intention. We must as intelligent beings be selective. I do not think for one minute that all people with epilepsy can play an important part in our societies but many can who have been emarginated and not given a worthwhile chance. We often fail to recognize our own prejudices and also to notice when our society discriminates. It really does exist. People should accept this as a starting point. At least certain attitudes in our police force have been recognized by seniors. Things can now hopefully only improve.

I have tried to outline certain important aspects of epilepsy in this essay. Some are personal experiences which I believe will ring true with many other sufferers whereas others are mere reflections.

(a) We should always remember that an epileptic condition might not be cured by drugs alone but also by the sufferer's ability to find an inner peace and peace in a society which might mean having regular and satisfying employment with a reasonable income, having good friends and a stable relationship perhaps with an understanding person of the opposite sex.

(b) A person with epilepsy should be known not only from the outside but more importantly within. More should be done to help the sufferer to understand the world and to construct his or her own stable views and opinions. Educating people is of paramount importance but the knowledge must be accompanied by that compassion which would enable the sufferer to take an active part in society.

(c) The concept of freedom in the educating process is very important. Families should not be overpossessive. Children can only develop in an atmosphere of freedom. I always remember the expression 'Ungrown-up grown-ups' by the famous liberal educational philosopher A. S. Niell. Society should be there to support and help at all times. As the Arab diplomat said, many of our problems stem from our desire to overgeneralize. We should remember this.

I believe that whatever comes out of this, it must be that a much more exhaustive research and questioning should take place along with a very forceful drive on the part of those interested to inform the public. As one very intelligent woman in her forties said to me 'If I hadn't known you personally and your difficulties, I would have known little or nothing about epilepsy especially the social psychological side of the illness. I have never been informed by the media.' She was certainly not alone in this. There are millions like her out there. We perhaps think that we are reaching more people than we really are. That is our real challenge for the future.